An Orange Socks Sibling Story - Nathan: MPS

Interview by: Gerald Nebeker, President of Orange socks

Gerald: I am so glad that Nathan took the time for an Orange Socks sibling interview over the phone about his brother, Nick. I learned a lot, and I'm sure you will, too.

Gerald: Nathan, thank you so very much for taking the time to meet with me via the phone to talk about your brother. This is unique because Nick is your twin brother. Tell me about his diagnosis.

Nathan: Thank you. My brother Nick has something called MPS or mucopolysaccharidoses, type 2. MPS is a lysosomal storage disorder, a genetic condition that only affects boys. He has a mutation in the X-chromosome that causes him to be deficient in an enzyme that breaks down tiny little sugars in his body. Because he was born without this enzyme, these sugars have accumulated throughout his body and caused symptoms that affect the nervous system, cardiac system and basically every system in the body. Nick is 19, is non-verbal and at the function level of about a five-year-old.

Gerald: You've obviously spent your 19 years with him, and he's all you've known as a twin brother, so when did you notice that Nick was different from you in a significant way?

Nathan: Because of his condition, we basically grew up in a hospital. My brother had two bone marrow transplants when he was around the age of three. So growing up, it was complicated. I pretty much lived at the hospital. I think that's when I realized that my brother was different. He required more care than other people and more attention, so I would say around the age of three was when I realized something was different.

Gerald: What was it like growing up with Nick? How did that work with your friends? What was your experience with him?

Nathan: Growing up had its ups and downs. First of all, Nick's disease is a very debilitating disease, so it was hard to understand why my brother could never talk. He would sometimes say words or noises that sounded like animal noises, and that was confusing to me, especially when I was very little, just understanding why my brother was different. Another really hard part was communicating that difference to my friends. I went to a school that my brother did not attend, so when I invited my friends over to my house, my friends would see my brother for the first time and would be curious as to why he didn't talk. When I didn't really even know that answer, it was difficult trying to explain that to my friends. The other thing that was also difficult was the staring, that was a huge challenge. Whenever we went out in public, people would stare at my brother. He would be in a handicapped stroller, kind of like a wheelchair or a huge chair, so many people would look. I would always be upset as to why people were looking at my family, "Why couldn't they just give us some privacy?" It wasn't until recently that I realized they were staring because they were curious. They were not judging my brother, they just wanted to know more. That was challenging, and it took a long time to get to that place of acceptance.

Gerald: So, you had to come to terms with it yourself, at least out in society.

Nathan: Yeah, and I think meeting other people in the support group, and meeting other siblings of other family members was what really helped me to get to that place of acceptance. Reading their stories online was really helpful, but as a little kid, it was hard to understand that.

Gerald: Did your life experience then have an influence starting your organization? You may want to talk about that a little bit.

Nathan: Yeah, definitely. I run an online international support group that's called Siblings with a Mission, where we offer support to siblings and family members with diagnoses and backgrounds from all over the country. We have an online story column where siblings and families can share their experiences and share their stories about what it's like to be a sibling and what it's like to live with someone who has a disability. The main reason I started this was because the sibling experience was so unique, and not many people know what it's like. By hearing the stories, you can offer support to other siblings and also find support ourselves. It's a fun group, and I enjoy meeting other siblings through that. My brother definitely inspired me to create that group.

Gerald: It's a great organization. I'm familiar with it, and I'm happy that we can cooperate together as organizations because I think you're doing a wonderful work through your organization, so I applaud you for that.

Nathan: Thank you, Gerald. I appreciate that.

Gerald: Do you have other siblings besides your brother Nick?

Nathan: No, it's just us, me and my brother.

Gerald: Did you feel that you got less attention or more attention from your parents because of your brother? Did you ever wonder why he's getting all this and I'm not getting a whole lot, or was that an issue in your home?

Nathan: Attention was a really big issue, and you see that from stories online that attention issues affect a lot of siblings. When I was talking about the example of growing up in the hospital when I was three and my brother was receiving his bone marrow transplant, my parents couldn't spend much time with me because they had to help my brother. When my brother was in the hospital, I spent most of my days with my grandparents. We stayed at a hotel close to the hospital, but I didn't really see my parents at all during that time. Several years later, my brother would need several surgeries and then see a few doctors for several years after that, and during those times, I didn't really spend much time with my family. I think what helped me was that my parents made a huge effort to share with me what was going on with my brother. That helped me to realize that I wasn't alone. I understood what my brother was going through. His healthcare providers were supportive and encouraging of my experience as well, so they always kept me up to date and informed, and that helped a ton. If my parents and the healthcare providers had not kept me involved, I think I would have felt very alone, so it was helpful that I knew what was going on at that time.

Gerald: What advice would you give to another young sibling whose brother has MPS? What advice would you give them and then what advice would you actually give parents in this situation?

Nathan: For a sibling, I would say be curious and do as much as you can to learn about your brother or sister's condition. As a sibling, you have a very unique experience; not many people have the opportunity to understand disability by having a brother or sister with one. That's what makes you unique, and that's what makes you special. I would say to go to the internet and to your brother or sister's health providers and ask what's going on. That will help you understand the situation, and it might also help you in the future when you have to take care of your brother or sister. Be curious, ask questions and ask your parents what's going on, and if for any reason you don't get those answers, keep trying. One thing that was really helpful for me was when I was growing up, I became really close friends with my brother's healthcare providers, and to this day, I still stay in touch with all of them. It was a really strong support network, and I've been able to learn so much about my brother's condition just by working and staying in touch with his providers. For parents, I would say just keep in mind how unique the sibling experience is. It's a special experience that can be very challenging at times, especially since siblings can feel alone, so as a parent, try to keep the non-disabled sibling involved as much as possible. It might also help to look up online about the sibling experience just so you can be aware of some of the emotions they are going through.

Gerald: Awesome, thank you. I really appreciate the information. Any closing remarks or any last thoughts you might have?

Nathan: I have lots of last remarks, so I would just say as a sibling, spend as much time as you can with your brother or sister and make the best of every moment. Keep in mind that you have a unique experience, and while it might be difficult to experience challenging situations and difficult to watch people stare at your brother or sister, just know how special and unique you really are to have the opportunity to understand disability. There are so many challenges that come with disability, and you have been given this unique experience to understand special needs and what it's like to have special needs. Enjoy that experience and make the most of it. Also, try and find a strong network of support, whether that be with your parents, with your friends, with your teachers or with your healthcare providers, make those connections, because later on in life, they will be important to you. Whether it be by sharing or reading stories from Siblings with a Mission, or at Orange Socks, or other support groups that are online, go out there and read and share your stories, and just know how your story can make a difference.

Gerald: Very good. Thank you so much for taking the time out of your busy life. I know you’re way busy. I’m excited to share your story out there so others can benefit.